

I'm Sick and Tired of Being Sick and Tired: Living with Post-Viral Fatigue

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Illness is a social issue, not simply a personal affliction.

—Arthur Frank *The Wounded Storyteller*

I had to remind myself that I had lived through it, already. I had known the pain and survived it. It only remained for me to give it voice, to share it for use, that the pain not be wasted.

—Audre Lorde *The Cancer Journals*

When I think of my illness, I immediately associate it with David and the divorce. I think of the word 'betrayal.' David suddenly and without warning ended our marriage. This betrayal hit me extremely hard. One day my marriage was on; the next it was over. On March 16, 1995, two weeks after he called telling me he had filed for divorce, I collapsed on the floor, my body unable to support my weight, let alone walk. Five months of being on pain killers to be able to perform the most basic of daily functions was just the start of my dealing with post-viral fatigue on a day-to-day basis.

Medical anthropologist Arthur Kleinman writes, 'The fidelity of our bodies is so basic that we never think of it - it is the certain grounds of our daily experience. Chronic illness is a betrayal of that fundamental trust' (45). In the divorce, David betrayed me, whereas in the illness, it felt like I betrayed myself. My own body and mind's betrayal seems much larger than David's betrayal. The divorce was bad; the illness is worse. Yet I know the two are intimately related. I have been struggling with this idea. Intellectually I can grasp that my body was actually trying to take care of me by shutting itself down, by trying to get me to slow down, reassess, and take care of myself. Reading studies about sudden bereavement and its impact on the immune system makes me realize that my body's reaction was normal under the circumstances. Yet, it still felt like a betrayal.

The 'mind vs. body' self-division was very strong. The intensity and the duration of the pain I was experiencing made my body into an 'it,' an other, an alien that was hurting me. 'It' hurt me, rather than 'I' hurt. Now the pain is less and I've accepted that it is not 'other' than me. Now I hurt, which is a step forward, but I'd still prefer being in a place where 'I hurt' could be replaced by 'I don't hurt.' Complete freedom from pain may not be possible, and I'm finally at a place where I can accept that. Maybe.

I have also been struggling with the fact that I feel at the will of my body. I have no conscious control over it. I can't simply will the illness away. Believe me, I have tried numerous times and failed. In fact, I've realized the harder I try to overcome my body through sheer will power, the more I struggle, the worse it gets. It's like I'm fighting against myself. The more I have been able to accept that my body has its own internal logic and to stop fighting, the more I've been better able to deal with the pain. Acceptance is key. But at times acceptance is so hard. For most of my life, I lived with the idea of mind over matter, of mind over the body, of being able to take my body for granted, of being able to command it to perform at will. In some ways, grieving this loss of control feels as significant as grieving the loss of my marriage.

Yet even as I acknowledge that I have no conscious control over my body, I have also learned that paradoxically, on another deeper level, I do. The more I've listened to my body - rather than commanded it to obey - and the more I have made conscious decisions to change my lifestyle based on this listening, the more I have regained health. By consciously taking control of my life, I have changed my eating, drinking, and sleeping habits, and my relations to friends, family, and work.

I eat more fruits and vegetables, less meat, especially red meat, and less pre-packaged prepared food. Rather than my pre-illness six hours of sleep, I now sleep ten to twelve hours nightly. And I often slip away quietly to take a nap. I've given up alcohol and caffeine completely since they intensify the joint and muscle pain.

Since the people who most often suffer from chronic fatigue syndrome seem to have the personality traits of being both overachieving and overly responsible for others, I've had to rethink my intense commitment to work and to question my caretaking and over functioning for family and friends. I now do yoga regularly, a practice I started four years ago. I am also now back in my karate class, which I'd had to give up for a year and a half when the pain was at its worst and which has proven a good indicator of the gradual improvement of my physical comeback.

I've had to revise who I am and how I function in the world in order to be healthier. With each change, I've experienced less pain and less illness. Yet, I'm not fully recovered. The changes I've undergone are substantial, yet not enough. On some basic level, I still am dealing with pain on a day-to-day basis. Granted the degree of pain has dropped so substantially that it is minor in comparison, yet it is still there, the backbone of my daily existence.

This seeming contradiction at the heart of my illness where it both is and isn't beyond my conscious control stumps me. How can I fully understand my illness? How can I present my relationship to my illness to others? Part of this quandary goes back to our Western cultural split into mind and body. As the editors of *Pain As Human Experience: An Anthropological Perspective* note, whether one follows the bio-medical approach or the psychological approach to understanding illness, in each 'The Cartesian dichotomy remains unquestioned. Both traditions tend to ignore how a person's immediate experience of pain unites its bodily, psychological, and social origins' (10). For now, in terms of my own healing, I am trying to accept where I am and to have faith that the more I listen to my body, the more I acknowledge that mind and body are interconnected, the more I will resolve this apparent contradiction.

In looking back, my journal entry, dated April 3, 1995 written approximately two weeks after the illness started, reads: 'I have more doubts and fears than I've ever had before. Considering also that at this point in time, I also have more physical pain and illness than ever before, the two must be related in some way.' My intuitive insight was validated once I started reading medical anthropology and related books.

In reading Arthur Frank's *The Wounded Storyteller* and Arthur Kleinman's *The Illness Narratives*, I've come to understand how the body is a bridge between the self and the social world. Frank writes, 'Bodily symptoms are the infolding of cultural traumas into the body' (28). Quoting research done by Arthur and Joan Kleinman, Frank notes, 'Symptoms of social suffering, and the transformations they undergo, are the cultural forms of lived experience. They are lived memories. [Symptoms] bridge social institutions and the body-self' (28). In *The Illness Narratives*, Kleinman says illness is the locus of cultural fears (18-20). He develops the idea that where there is illness, there is conflict between what one desires and what is expected, between what one desires and what is available, or perhaps between two conflicting desires (97). Where there are limitations, culturally imposed or self-imposed limitations, illness easily enters the picture.

In my own case, my efforts to bridge the two worlds of Lambert, Montana - an agricultural world, traditionally conservative, based on physical labor, with a strong sense of community, where the people are as involved as their livestock in the natural process of procreation - and the University of Nebraska-Lincoln, where I work on my PhD and teach - an academic world, very modern, based on intellectual labor, individually orientated, and extremely competitive, with people concentrating their energies on the reproduction of texts rather than babies - has caught me between two strong desires, one to be the nurturing mother who is central in the community and to be the hard hitting academic whose career takes number one priority in her life. All along, I've wanted both options and I thought that I would be able to take my core values from Lambert, Montana, which are basically 19th century values in many ways, and transplant them to academia in late-twentieth century America. But this melding of options hasn't been possible.

The second desire, to be a self-actualized modern woman, puts the family-comes-first value in conflict. On some level, David's concern that I couldn't be a 'good' mother because I didn't cook regularly takes this core issue and simplifies, reduces it to its very essence: Traditional woman vs. Modern woman. I would laugh at him, saying 'We're both responsible adults - our children wouldn't go hungry!' But for him, a choice ultimately had to be made: either I was a traditional woman or I was a modern one. And since in his mind, he couldn't cook for a family, divorce and starting his new family with a traditional self-effacing wife was his solution.

His solution left me with less than half of the equation in place. I had a career that I was working toward, but I wasn't yet in a place where that was a given. And with David's dramatic break, I had no option of starting a family anywhere in sight. And with the intensity of my love and commitment to him and to the ideal of family, I didn't have the option emotionally to divorce myself from him quickly in order to put other relationships in place, let alone divorce myself from the ideal of family. Being in my mid-thirties intensified this sense of loss of the potential for a family; perhaps, if I had been ten years younger, my sense of loss may have been less or of shorter duration.

My grieving for David was much more than for the loss of one man - and if it had been only that, it would have been intense enough in itself. But it was also for the loss of the possibility to start a family that I had felt was long overdue. Also, it was for the loss of a way of understanding and being in the world. I had thought I could be a traditional woman in a new modern setting, that I could transpose the values of one culture to another. Well, that doesn't work very well.

I was willing to push the boundaries of Lambert's world view as long as I had the family-center still strongly in place. Because I now understand how David's leaving me and leaving me childless threatened the whole system and thus my whole concept of self, it is hard for me to simply start pushing outward again, picking up where I left off. I'm afraid that I will be pulled even farther apart with my two worlds having less and less in common. This is good for me to recognize. It makes me realize that it isn't 'fear of failure' that had stalled me in the dissertation process, although that is real enough, but rather 'fear of success' or perhaps more aptly, 'fear of the unknown.' Until I come to terms with the core conflict of my strange version of being bi-cultural with two opposing worlds, I will continue to be torn by my ties to Lambert.

With David at my side I felt free to question, challenge, negate, denigrate, and reject any of Lambert's conservative, old-fashioned values. I felt David was undergoing some of this process himself, intellectually distancing himself from his own conservative background. With David at my side, especially with his negative attitude toward Lambert and what he termed its 'back-asswardness,' it was easy for me to leave Lambert behind. This was my mistake and my downfall.

Because I wasn't yet strong enough to claim myself as my own center, pulling away from Lambert gave me no center other than David himself. Lambert's attitude about David didn't help the situation. When I moved in with him without marrying him, my morally outraged parents disowned me, with my mother telling me that I was a 'scarlet woman' and that I was 'no longer marriageable on the marriage market' and with my usually calm and quiet father yelling at me and slamming down the phone. The larger community not only supported my parents' decision but did their own share of ostracizing me. The very conservative nature of the community presented an either/or choice. It was either my family and Lambert's values or David and the intellectual world he offered me beyond Lambert.

At the time, I chose David and hoped my parents at least would reconsider, which with time they did. Getting married after five years of 'living in sin' definitely helped to reinstate me in many people's good graces. It's interesting to note that now with the divorce, some of the Lambert community are back to not knowing what to do with me. I just don't fit any of their known and accepted categories. A divorcee is strange enough, but at least if I were a divorcee with children, I would still have an acceptable role to play. A woman without any children is, putting it bluntly, a freak. By aligning myself then with David, even at the price of being disowned, I can see how I had taken the first steps in cutting myself off from my roots, my beginning. This self-division where I was torn between two cultures helps me understand why when David left, I felt as if he had taken my world

with him. No wonder I collapsed.

As I've reclaimed more and more of my connections with my past, both with the people of Lambert and with some aspects of the lifestyle - such as my love of horses, country-western dancing and being outdoors - I've regained some of my core sense of self. If wranglers, cowboy boots, the foxtrot and jitterbug are my birthright, I want to claim them. I'm realizing that if I am to survive as a whole person, I need to give up the idea of an either/or choice, either Lambert or David - or since David is history, either Lambert or UNL - and start embracing both/and.

I've also realized that Lambert's defining me as 'body' and UNL's defining me as 'intellect' both partake of a patriarchal ideology that limits my potential as a fully developed woman. Based on my individual/cultural history, if I do fall into the either/or trap of choosing one option over the other, I will still be self-divided. I don't want to put myself in the position where I feel I have to choose one or the other ever again. I also realize that if before in some ways I was rejecting Lambert, partially in response to Lambert rejecting me, I don't want now to reclaim everything I've rejected. Some of Lambert's values never did nor ever will work for me. Lambert's world view grants women the rights to motherhood while denying them the rights to a career and to self-actualization. I left Lambert challenging the idea that I couldn't, shouldn't have both a family and a career. I'm still challenging it. I still want both.

But I no longer want both no matter what the costs to myself. I no longer want to go about achieving these two life goals without the greater self-awareness I've gained through my illness. I am coming to understand that if my chance of being a mother never happens, I don't have to accept Lambert's definitions of me - or my own internalization of these values - as being a failure. Extending this same logic to UNL, I am coming to understand that if my chance of being a full professor at a prestigious research university never happens, I don't have to accept academia's definition of me - or my own internalization of these values - as being a failure either. Thanks to my illness, I've begun to question the cultural expectations of my two dominant cultures and to question my easy acquiescence to these imposed values. I hope that this process will eventually take me to the place where I can free myself to find my own path of success in both worlds.

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